

“unusual and interesting woman”

A personal experience of parental blame

Bernadette Louise

ADASS research participant and reference group member

I am a parent of two diagnosed autistic children, with ADHD, OCD and PDA

I am also late diagnosed autistic and ADHD myself

I'm a Parent Carer Forum Representative and Co-Chair

I was previously Co-Chair of Worcestershire Autism Partnership Board

Until Recently I was the Strategic Autism Champion for the H&W ICB

Worked on Autism Research projects for University of Gloucestershire

An ADASS, Reference Group and Research Participant

I have experienced Parental Blame and accusations of FII.

What I should have opened with...

**Bernadette
Louise**

Mother

Artist

VIVID

140 Heath Mill Lane
Birmingham | B9 4AR

T: 0121 766 7876 | E: info@vivid.org.uk
http://www.vivid.org.uk

SAT 18 & SUN 19 FEB DEATHTRIPPING

The Garage presents... *DEATHTRIPPING* - a festival of trash film and performance curated by Bernadette Louise. The programme features seminal video works from experimental filmmakers Nick Zedd and Richard Kern alongside live performance from the legendary Lydia Lunch.

What Goes On In This House, Stays In This House

Multimedia Performance Art by Bernadette Louise

Live at Fierce Festival 2008

26 May, 4pm - 8pm & 27 May, 6pm - 8pm

Birmingham Hippodrome

A peep behind suburbia's twitching net curtains, Bernadette Louise constructs an elaborate multimedia narrative creating a domestic space that is both a place of comfort and a claustrophobic prison. Audiences are placed in the role of peeping tom, provoking our voyeuristic curiosity as we witness uncomfortable secrets normally swept under the carpet.

There is also Audio and Video content that can be observed online.

Tickets £5 each
Box Office: 0870 730 1234 www.bernadettelouise.com
www.fiercetv.co.uk

LOTTERY FUNDED
FIERCE Age 14+



Why this matters...

Only a Phone Call Away



Featuring
Lydia Lunch
Bernadette Louise
Louis Campbell
Nicole Blackman
Geordie Blake
Big Bren

0121 314 3330 or 0845 867 3853

Audio voyeurism that gives you a sense of cinematic presence within the theatrical backdrop of an overheard telephone conversation.

Trespass amongst the personal spaces of Lydia Lunch, Nicole Blackman, Geordie Blake, Louis Campbell, Big Bren and Louise herself.

Only a Phone Call Away is exactly that, call either 0121 314 3330 or 0845 867 3853 (calls charged at local rate) at any point throughout the Fierce! Festival.

Will you wrestle with your conscience and eavesdrop into the private lives of the unknowing?

FIERCE TEN
ARTS COUNCIL ENGLAND
19th May - 2nd June 2007

barbican

The Surreal House

barbican artgallery

10 Jun - 12 Sep/10
Tickets online from £8

101 things to do this summer
barbican.org.uk/101

emergency

FRIDAY 1 OCTOBER 5PM ONWARDS
& SATURDAY 2 OCTOBER MIDDAY ONWARDS

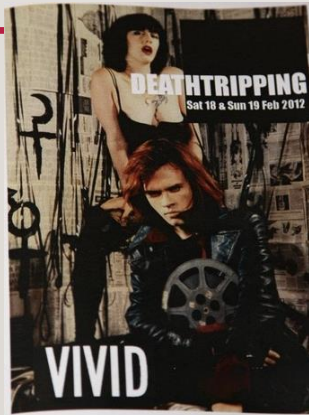
emergency is our annual and extraordinary free marathon of the bizarre and the beautiful, the glamorous and the thought-provoking. Now entering its second decade, last year's tenth epic saw a mermaid and a giant post-box, paddling pool performance and tea parties, romance and heartbreak in a tent and a mass celebratory conga. Expect 40+ performances filling every nook and cranny of greenroom and spilling out onto the street.

E: emergency@greenroomarts.org W: emergencymc.posterous.com

Part of The Manchester Weekender. Forty-eight hours in the life of the city

ARTS COUNCIL ENGLAND MANCHESTER CITY COUNCIL AGMA THE MANCHESTER FOUNDATION

greenroom 54-56 Whitworth St West, Manchester M1 5WW
T: 0161 815 0500 W: greenroomarts.org



"unusual and interesting woman" ???

Experienced parental blame at the most extreme, being accused of 'significant emotional harm' Section 47 Child Protection.
Why?

I challenged poor practice and dismissive attitudes

I made a complaint about a senior clinician

provided evidence and comments on reports (at professional's request)

researched my child's needs when we were not getting answers

Communicated differently, passionately, and preferred to send emails

held personal views on childcare (e.g. mother's at home matter)

Came across as anxious (and I was, because the situation was incredibly stressful)

What they said Just some of the comments...

Concerned that
he wasn't
allowed to take
therapeutic risks

The power
balance was
wrong,
excessive
negotiating

Parents are
anxious so
making child
anxious too

“Bernadette was talking very fast and during clinic her neck became red and blotchy she appeared to be very stressed. This did subside after a while. I asked if she wanted to come to ‘Triple P’ discussion group and she said she felt it would be a waste of time. She also expressed her concerns about homestart and didn't want a volunteer knowing her business before she knew who they were. Bernadette is still taking medication for her anxiety and depression.”

What they said Just some of the comments...

My art was revealing as an insight to my state of mind

That I was manipulative, not happy with services (if not getting what I want)

I was asking for a referral to the children with disabilities team

I was shouted to down the phone by a professional, “he doesn’t have a disability”. They were wrong

Everything we did was correct, in terms of meeting our son where he was at, understanding his limitations...then I discovered PDA and it all fell into place...it didn’t help, it made matters worse.

Key Findings

The findings demonstrate that parental blame is not an isolated issue resulting from individual practitioner behaviour. Rather, it is a systemic phenomenon that emerges at the intersection of workforce capability, service design, organisational culture, safeguarding practice and wider social and political narratives about autism.

Parents reported widespread experiences of being disbelieved, judged, criticised or viewed with suspicion when seeking support for their child. These experiences frequently occurred before diagnosis and were associated with significant emotional harm, trauma, loss of trust in services and, in some cases, safeguarding interventions and allegations of Fabricated or Induced Illness (FII).

We know our children. We notice patterns, changes, distress, communication challenges and needs.

But for many us, particularly where there are complex needs (PDA is one of those), the knowledge we hold can sometimes be interpreted differently.

A parent who is persistent can be seen as difficult.

A parent who challenges can be seen as unreasonable.

That is where parental blame can begin. And then add in the extra layer of being autistic ourselves, ACCUSED.

The Artrix gallery brings the best in challenging new work to Bromsgrove in its monthly exhibition programme of 2D, 3D and mixed media artwork.



BERNADETTE LOUISE: Accused - An Autism Mother

Wednesday 1st – Sunday 26th
February

Bernadette Louise creates a spectacle of oversized Healthcare posters emphasising the 'invisible' symptoms of Autism Spectrum Disorder, Pathological Demand Avoidance. In a response to the authorities, she uses images and quotes from the assessment process to highlight a desperate need for PDA Awareness. On Monday 20th February there will also be an evening of poetry and spoken word with popular Autism Vlogger, 'Autistic Genius' and Bernadette Louise.
www.bernadettelouise.com

ACCUSED

'MS G' ADVISED IN HER INTERVIEW THAT YOU WERE AN
**"UNUSUAL AND
INTERESTING WOMAN"**

"I HAVE COME ACROSS A COUPLE OF WEB SITES THAT MAY SHED A LITTLE LIGHT ON THE BACKGROUND OF BERNADETTE (MOM). It IS HER WORK WEBSITE [HTTP://BERNADETTELOUISE.COM /INDEX.HTML](http://bernadettelouise.com/index.html) AND THE COMMENTS AND PHOTOS ARE QUITE REVEALING AS A POSSIBLE INSIGHT TO HER STATE OF MIND. THERE ARE ALSO A COUPLE OF VIDEOS ON "YOU TUBE" THAT CAN ALSO BE VIEWED. ALL I HAVE SEEN ARE IN THE PUBLIC DOMAIN.

I HAVE SPOKEN WITH 'D' REGARDING THIS AS TO WHETHER TO BRING THIS UP AT THE TAC WITH OTHER PROFESSIONALS BEFORE MOM ARRIVES.

IT MAY INDICATE THAT BERNIE MIGHT NEED SOME PSYCHOLOGY INPUT.

"SANDRA"
NURSERY NURSE
SCOTT ATKINSON CDC"

Chief Executive Response 16/19/2016 page 3 - 5

"SHE WAS CURIOUS ABOUT YOU AND THE FAMILY AND THEREFORE LOOKED ON FACEBOOK INITIALLY"
'MS G' ACCESSED THE WEBSITE AND READ A VERSE ON THE WEBSITE THAT FRIGHTENED HER AND GAVE HER CONCERNS FOR THE WELL-BEING OF THE CHILDREN. I UNDERSTAND THE IMAGES ON THE WEBSITE CONCERNED HER.
'MS G' WAS CURIOUS ABOUT YOU, HAVING BEEN INVOLVED WITH BOTH YOU AND THE BOY AT THE CHILD DEVELOPMENT CENTRE. SHE TALKS FONDLY OF THE BOY AS A "LOVELY LITTLE BOY"
'MS G' THOUGHT SHE WAS ACTING IN THE BEST INTERESTS OF THE BOY AND THOUGHT SHE HAD INFORMATION THAT SHOULD BE KNOWN BY OTHERS INVOLVED IN HIS CARE"

ME: WHAT QUALIFIES ANY MEMBER OF THE TRUST TO SUGGEST THAT I NEED PSYCHOLOGICAL INPUT?

CHIEF EXEC: "CAN I ASSURE YOU THAT THE TEAM WERE NOT ASSESSING YOUR NEED FOR PSYCHOLOGICAL INPUT."

COMPANY SECRETARY (ON BEHALF OF CHIEF EXECUTIVE)

It was frightening & lonely. I thought we were a one-off, a rare case, because no one was talking about it.

Until I spoke out about it publicly, then I was inundated by similar stories from strangers.

There was no one able to help during that time, or after, so I used the only tools I had to make sense of what happened.

ACCUSED

"SLT - ATTENTION IS STILL DELAYED, HE IS SINGLE CHANNELLED. THERE IS CONSTANT REPETITIVE QUESTIONING TO ADULT DUE TO HIS ANXIETY. UNDERSTANDING - ECHOES A LOT BUT ON FORMAL ASSESSMENT DOING OK AND COOPERATED WELL. EXPRESSIVELY HE STRUGGLES A LITTLE BIT, FOUND IT HARD TO GENERATE HIS OWN LANGUAGE, RELIES ON ADULT LANGUAGE AND LEARNT PHRASES. HE TRIES TO INITIATE INTERACTION BUT CAN GET TOO CLOSE. MAY BENEFIT FROM A PRESCHOOL LISTENING GROUP. NEEDS VISUAL PROMPTS TO HELP WITH CHANGES OF ROUTINE AND WHAT HAPPENS NEXT."

SPEECH AND LANGUAGE THERAPY REPORT 8/3/15

"DURING THE INITIAL INTERVIEW, MUM REPORTED CONCERNING BEHAVIOUR: THE BOY'S ATTENTION AND LISTENING SKILLS AS 'THE PROPORTION TO AN ADULT' AND THAT HE 'SAYS THINGS THAT HE DOESN'T MEAN'. THEY ALSO SAID HE WAS 'VERY OBSSASSED' ABOUT CERTAIN 'PHRASES' - SAYING 'TO COME THE SAME THEM WHEN OUT SHOPPING. PARENTS WERE ALSO CONCERNED THAT THE BOY SEEMED NOT TO BE AWARE OF SOCIAL BOUNDARIES AS HE WOULD KISS PEOPLE ON THE CHEEK AND TRY TO BRING THEM INTO HIS ROOM. HE TRIES TO INITIATE INTERACTION BUT CAN GET TOO CLOSE. MAY BENEFIT FROM A PRESCHOOL LISTENING GROUP. NEEDS VISUAL PROMPTS TO HELP WITH CHANGES OF ROUTINE AND WHAT HAPPENS NEXT."

When I arrived at the house, the boy appeared happy to see me and was keen to talk and in fact got that point quickly. He was shorter and seemed to come up to my 'BUZZ LIGHTYEAR' toy. He was repeating words as he was talking about his toy, but this did not prevent him from getting his message across and actually over the course of this visit, Cain's fluency improved. For the rest of the visit he was generally very fluent.

He is able to use eye contact and he can maintain this. He will take part in a conversation, although he may not always respond when he is spoken to, so this may be on his terms at times. During play he will listen to what has been said, but again may choose not to follow what is asked. At one point during the visit, the boy got very upset that I was playing with his bricks and he did not like this and he started to cry. However, this was short lived and he was able to then accept this and the involvement of his younger brother.

During the visit, the boy was seen to be very active at times. He liked to play between the two rooms downstairs and he also seemed to come on the sofa, make a jungle and play hide and seek. He was also seen to be able to hold on to his toys that were available for him to play with. He does benefit from adult support to maintain his attention.

A formal assessment of the boy's receptive language skills has not yet been carried out. It is inappropriate to do this at the moment as the boy does find it difficult to consistently follow an adult's lead.

The boy's expressive language skills do appear to be quite good. However, he does use many learnt phrases alongside his own spontaneous sentences. He does have a very extensive vocabulary.

South Atkinson Centre Speech & Language Therapy 21/10/15

"THE BOY'S ATTENTION AND LISTENING ARE STILL DELAYED."

THE BOY IS KEEN TO INTERACT AND CONVERSATION WITH PARENTS ASSESSED IN THE CLINIC INTERVIEW. HE CONTINUES, HOWEVER, TO USE MANY LEARNED PHRASES ALONGSIDE HIS OWN SPONTANEOUS SENTENCES. E.G. "WELL, I'M HAPPY TO GO TO THE STORE TO GET THE BREAD WE NEED TO BUY". THERE IS ALSO EVIDENCE OF ECHOLALIA WHERE THE BOY WILL REPEAT THE ADULT'S LANGUAGE IMMEDIATELY. "MUM, I'M HAPPY TO GO TO THE STORE TO GET THE BREAD WE NEED TO BUY". THE BOY'S USE OF QUESTIONS HOWEVER, CAN BE VERY REPETITIVE. "MUM, I'M HAPPY TO GO TO THE STORE TO GET THE BREAD WE NEED TO BUY".

"AGREE HE IS A TYPICAL 3 YEAR OLD BOY"

SPEECH & LANGUAGE THERAPIST, CHILD PROTECTION MEETING 17/12/15.

ACCUSED

"MUM HAS CONSISTENTLY REPORTED THE FOLLOWING: SHE STRONGLY FEELS THAT THE BOY HAS PATHOLOGICAL DEMAND AVOIDANCE - NO PROFESSIONAL INVOLVED IN THE BOY'S CARE FEELS THERE IS ANY EVIDENCE FOR THIS DIAGNOSIS."

REFERRAL TO CHILDREN'S SERVICES. "EMMA" OT

"Mum also reports the following: Boy is hyperactive - I said that. He falls so excessively that they cannot allow him to walk anywhere - I didn't say that. He's so clumsy and puts things in his mouth so often that it is unsafe for him to play in the garden - I kind of said that. BOY REPORTEDLY ASKS EXCESSIVE QUESTIONS FOR REASSURANCE and makes himself sick if he has to go to nursery - That is absolutely true. Boy reportedly dislikes objects around the house and the family now have a dedicated "wrong room" for anything boy doesn't like. The family can't go in to supermarkets because boy runs away. He is not safe with other children as HE SQUEEZES THEM and doesn't know how to interact. BOY REPORTEDLY PULLS AT HIS HAIR. BOY REPORTEDLY FINDS IT DIFFICULT TO PLAY INDEPENDENTLY. BOY CONSISTENTLY TAKES RISKS."

"MUM HAS NEVER ATTENDED ANY MOTHER AND BABY GROUPS AS SHE HAS VERY STRONG DISTORTED VIEWS AROUND SOCIAL CLASS."

Professionals do not see the same difficulties in Boy that Mum is reporting and feel that parental mental health problems are leading to VERY DISTORTED VIEWS ON WHAT BOY NEEDS PROTECTING FROM and thus he is missing out on many typical childhood opportunities. Also it is strongly felt that PARENTAL ANXIETY IS CAUSING BOY TO BECOME EXTREMELY ANXIOUS.

MYSELF AND THE CONSULTANT PAEDIATRICIAN HAVE HAD LONGSTANDING CONCERNS ABOUT THIS MOTHER AND HER DISTORTED VIEWS AROUND HER CHILD'S PERCEIVED DIFFICULTIES"

At the child development team meeting it was agreed by all professionals INCLUDING CONSULTANT PAEDIATRICIAN 'DR A' that The boy should be considered for a STRATEGY MEETING to discuss likely FABRICATED ILLNESS.



"I WOULD LIKE TO REASSURE YOU THAT NO PROFESSIONALS HAVE EVER THOUGHT YOU WERE DELIBERATELY MAKING THE BOY ILL AND THEY ALL AGREE THAT YOU BELIEVE HIS SYMPTOMS TO BE TRUE."

"CAN I EXPLAIN THAT 'EMMA' MADE THE REFERRAL TO THE ACCESS CENTRE AS SHE AND OTHER COLLEAGUES WERE CONCERNED OF THE EMOTIONAL CONSEQUENCES THAT THE BOY MAY BE PLACED UNDER DUE TO YOUR LEVELS OF ANXIETY. THERE WERE OCCASIONS WHERE YOU THOUGHT THAT SOME OF THE BOY'S DEVELOPMENT WAS ATYPICAL, HOWEVER, THE PROFESSIONALS DIDN'T AGREE AND THEY WERE CONCERNED THAT MAY HINDER HIS OVERALL DEVELOPMENT."

"EQUALLY, THE TERM FABRICATED AND INDUCED ILLNESS WAS NEVER USED BECAUSE ANYONE EVER THOUGHT YOU WERE DELIBERATELY HARMING THE BOY AND I AM SORRY THAT THIS HAS INFLAMED THE SITUATION."

ACCUSED

"BERNADETTE WAS TALKING VERY FAST AND DURING CLINIC HER NECK BECAME RED AND BLOTCHY SHE APPEARED TO BE VERY STRESSED THIS DID SUBSIDE AFTER A WHILE. I ASKED IF SHE WANTED TO COME TO PPP DISCUSSION GROUP AND SHE SAID SHE FELT IT WOULD BE A WASTE OF TIME. SHE ALSO EXPRESSED HER CONCERNS ABOUT HONESTART AND DIDN'T WANT A VOLUNTEER KNOWING HER BUSINESS BEFORE SHE KNEW WHO THEY WERE."

BERNADETTE IS STILL TAKING MEDICATION FOR HER ANXIETY AND DEPRESSION."

"Laura", Farnham Key Worker, Early Help Hub, 15/8/15.

12 NOVEMBER 2015 15:11
"EMMA OT" to "DR A"

"THANK YOU FOR DOING THIS. THE FAMILY SUPPORT WORKER HAS BEEN ONTO ME A COUPLE OF TIMES ASKING HOW LONG UNTIL THE REFERRAL IS MADE AS THEY ARE KEEN FOR IT TO GO THROUGH QUICKLY AS MUM KEEPS ASKING FOR A REFERRAL TO THE CHILDREN WITH DISABILITIES TEAM TO GET A SUPPORT WORKER."

KIND REGARDS
"EMMA"

"LAURA"/"TRACY" EARLY HELP HUB, CHILD PROTECTION REPORT 30/11/15.

'LAURA' EXPRESSED THAT SHE FELT THAT MOTHER WAS 'MANIPULATIVE', NOT HAPPY WITH SERVICES (IF NOT GETTING WHAT SHE WANTS) AND OFTEN SHOWS AND IS IRATE AT PROFESSIONALS."

Help
Advice and support for families with children aged 0 to 19

We all need a bit of help sometimes...

Being a parent is hard. We all have difficult times and when problems arise it can be difficult to know where to turn for help.

Autism is widely misunderstood by professionals

Accusations of blame result in long term damage, trauma and risk of suicide

Autistic parents experience more parental blame

Parents' knowledge of their child is not recognised or valued and may be viewed with suspicion

Parents of autistic children have a high level of mistrust in services and professionals

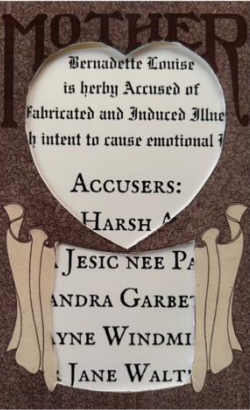
The current support offered is often unhelpful and sometimes does more harm than good

Parents of autistic children may be at increased risk of being subject to child protection proceedings and/ or suspected of FII

Parental blame is more likely to occur before a child is diagnosed as autistic

ADASS findings: The 8 key consideration areas

Ten Years on...



BERNADETTE LOUISE

We Are The Witches | 11 November - 16 December 2023 | The House of Smalls



Thank you

